

**Lyme Disease Advisory Committee  
Minutes of the July 09, 2002 Meeting  
Department of Health Services Sacramento, CA**

The seventh meeting of the Lyme Disease Advisory Committee (LDAC) was held on July 9, 2002, in Sacramento, California.

**Committee members**

Victoria Deloney, RN, Public Health Nurse  
Vicki Kramer, Ph.D., California Department of Health Services  
Robert Lane, Ph.D., University of California, Berkeley  
Peggy Leonard, Lyme Disease Resource Center  
Lee Lull, Lyme Disease Support Network  
Scott Morrow, M.D., California Conference of Local Health Officers  
Susie Merrill, Lyme Disease Support Network  
James Miller, Ph.D., University of California, Los Angeles  
Christian Parlier, Lyme Disease Support Network  
Raphael Stricker, M.D., California Medical Association

**Other attendees**

Anne Kjemtrup, D.V.M., Ph.D., California Department of Health Services  
Peter Mackler, California Department of Health Services  
Approximately 40 people representing the interested public and public agencies

**I. Welcome and introductions**

The meeting was brought to order at 10:15 a.m. Peggy Leonard, representing the Lyme Disease Resource Center and Victoria Deloney, representing public health nurses, were presented as two new members of the Committee. Peter Mackler from the Director's office welcomed the two new members later in the meeting.

**II. Review of minutes from March 14, 2002 meeting**

Minutes from the March 14, 2002 meeting were approved on May 29, 2002 and posted on the California Department of Health Services' (DHS) web-site.

**III. DHS Progress Report**

Dr. Kjemtrup presented a progress report on the California Department of Health Service's (DHS) tick-borne education and prevention activities since the last LDAC meeting in March 2002.

Education of the medical community: An article highlighting the nation-wide increase in Lyme disease (LD) case numbers and the removal of the LD vaccine was published in the July 1 *Action Report*, the quarterly newsletter of the California Medical Board. The Physician Questionnaire was revised and contacts were pursued to co-sponsor a Tick-Borne Disease Symposium for physicians. These issues are addressed in detail later in the meeting (see below).

Education of the General Public: The *DHS Today* monthly newsletter, distributed to agencies statewide, noted that May was LD Awareness month. The LD brochure was finalized, 10,000 copies printed, and brochures were made available at the meeting. The DHS website has been updated and has a separate section on LD. This section includes the brochure, the articles from *Action Report*, minutes from past LDAC minutes (all conveniently located under one button), vaccine guidelines for health care providers for any extant vaccine, and soon the tick testing data. Press contacts included providing information to the Oakland Tribune on the removal of the LD vaccine from the market and a press release on tick-borne diseases, issued May 8<sup>th</sup>. One radio station in southern California read the release in its entirety. Seven presentations on Lyme and other tick-borne diseases were given by several DHS biologists to public groups and agencies.

DHS Tick Surveillance Activities and Interactions with Other Agencies: DHS biologists, often in collaboration with local vector control agencies, surveyed for ticks in ten counties in California. Surveillance is performed for a variety of reasons including ongoing assessment of tick numbers, response to reports of increased tick numbers, and testing for various tick-borne disease agents. Ticks collected from Butte, Riverside and Los Angeles Counties were tested for the presence of *Borrelia burgdorferi*. These data will be included in the tick data posted on the DHS web site. DHS has received data from four public health laboratories that test ticks recovered from people. These data are being compiled in a new database that will eventually be posted on the DHS website. Tick-testing surveillance data was received from two local agency laboratories.

In response to a Committee question, DHS indicated that it is willing to include data on tick-testing from research facilities, however, this is often difficult because often the information is not compatible with the existing data format.

The Committee suggested that the statement regarding the removal of the vaccine from the market be placed at the front of the vaccine guidelines rather than on the last page where it is hard to find. DHS agreed to follow-up on this recommendation. The Committee also requested that access to the brochure be made easier from the DHS web site. DHS stated that groups are welcome to add a link on their web site to the DHS site, and that changes are being made to the DHS website that will facilitate access to LD information.

It was suggested that at the next meeting, the Committee revisit the goal matrix generated at the first two meetings because many of the goals have been met and it would be useful to review and/or revise other goals.

#### **IV. Public Education**

##### **A. Brochure Distribution**

A discussion was held regarding minor revisions to the text of the brochure. DHS agreed to immediately modify wording in the erythema migrans section of the brochure posted on the website and will include these changes when the

brochure is reprinted. At this time, DHS will not list *Bartonella* as a tick-borne disease agent until studies are published demonstrating that ticks can transmit *Bartonella* species. (i.e. This agent has been detected in ticks but transmission studies are not yet published.) Fact sheets on other tick-borne agents have already been reviewed by the Committee and will be posted on the DHS website soon.

Brochure distribution is traditionally carried out by DHS biologists who provide brochures to public parks, concessionaires, local agencies, etc. It is available for printing on the DHS web site. Other suggestions for brochure distribution included sending them directly to local health departments with a cover letter suggesting that older DHS brochures be discarded and replaced with the new one. LD support groups and other community-based groups are also encouraged to distribute the brochure. Establishing links from medical websites, such as Medical Consult, was suggested.

### **B. Tick Warning Poster**

An example of the revised tick warning poster was provided to Committee members for discussion. Revisions included using more realistic ticks in the warning sign, having an “actual size of ticks” box, and integrating the precautionary statements from the brochure onto the warning sign. Suggestions from the Committee included using words more specific to tick habitat, changing the order of some of the prevention bullets to emphasize the importance of self-checking and early tick removal, and suggesting that pets can carry ticks too. In response to a suggestion on including tick-testing on the poster, DHS stated that one problem with tick-testing is that the results must be carefully explained: a “negative” tick may result in a false sense of personal security because there may be other infected ticks that bit a person and were not detected. Limited space on the poster may not allow a lengthy explanation. Comments on the poster from the Committee were noted and another version will be distributed to the Committee.

## **IV. School Children Education**

It was pointed out that some local mosquito and vector control districts already have school-oriented health education programs. Other groups that may have education programs geared to elementary and high school age children, such as 4-H, are being investigated as possible avenues for education programs. Suggestions from the Committee included placing the brochure in immunization material, contacting groups such as Girl and Boy Scouts and the PTA, and creating a hand-out specifically written for school-age children. Public Service Announcements on Public Television, particularly in those areas of high endemicity, were also suggested. It was pointed out that DHS would be most effective working at the regional level, e.g. with school districts.

## **V. Physician Education:**

The reformatted physician questionnaire was presented. The one page assessment form is designed to be included in a mailing such as the California Medical Board's quarterly newsletter, *Action Report*. It specifically assesses those issues that can be addressed by a DHS education program and is short and easy to fill out to encourage a high response rate. The Committee made several comments and suggestions. A revised version will be forwarded to the Committee. The methodology of doing a broad-based assessment, and incentives to encourage response, were discussed.

Several University of California medical schools who give Continuing Medical Education (CME) courses and other CME-granting agencies were contacted to determine interest in co-sponsoring a Tick-Borne Disease Symposium. Responses from these organizations are pending. Several physician associations were also mentioned by the Committee as potential co-sponsors. The symposium would consist of 2-3 speakers, including physicians who are currently treating patients with LD, and would be 1 hour long.

## **VI. Public Comment**

It was stated that due to the number of people asking to speak during the public comment period, speakers would be strictly held to the three-minute time limit. If more time is needed, speakers need to send a request to Dr. Kjemtrup ([akjemtru@dhs.ca.gov](mailto:akjemtru@dhs.ca.gov)) who would then forward the request to the Chairman of the Committee for consideration of granting additional time.

The following people offered comments:

Herb Dorken: Dr. Dorken gave an overview on the status of the Senate Bill 2097 that amends previous legislation regarding the composition and function of the LDAC. He mentioned legislation, Assembly Bill 2125, that would expand workers compensation coverage for peace officers, forestry, and fire protection to include LD. He mentioned Assembly Bill 2168 that is an amendment to the personal income tax law and deals with income retirement benefits; this may benefit Lyme patients who retire early. Dr. Dorken suggested that the LDAC attempt to find out why physicians are not reporting LD cases and find out ways to facilitate LD reporting. In addition, he felt that the LDAC should make recommendations on appropriate light-colored clothing for State workers who work in tick-infested areas.

Earis Corman: Ms. Corman stated that the best way to get out LD information would be via a 30 second television info-mercial such as those produced by the Electricity and Water Board.

Meg Hughes: Ms. Hughes stated that LD support groups would be effective in distributing brochures on behalf of the State of California, particularly if they could say that they are distributing on behalf of the State.

Diane Wilcox: Ms. Wilcox stated that she felt it was important to have an educational professional on the Committee to be able to develop age-appropriate material.

Philip Hammond: Mr. Hammond stated that in San Francisco City and County health clinics, despite great sophistication, physicians in these clinics do not recognize LD. He stated that unless a patient presented with an EM rash, physicians did not test for LD. He felt the brochure would help educate people in the clinics. He said that the brochure was a good start and added that the map on the front was excellent.

Karen Chew: Ms. Chew presented comments on the physician questionnaire and expressed the wish that it would have more diagnosis and treatment questions to educate physicians at the same time. She also proposed trying to offer CME as an incentive to reply to the questionnaire.

Roy M<sup>c</sup>Namee: Mr. M<sup>c</sup>Namee stated that, in relation to his wife's illness, after 3 ½ years of going through terrible things, they finally figured it out themselves, and found a physician that would treat his wife. Mr. M<sup>c</sup>Namee felt that it is the responsibility of DHS to disseminate the information on LD, officially and through appropriate channels. While support groups are helpful, information distribution should not rest with them. Information on LD prevention must be mandated officially, such as through DHS, not offered on a voluntary basis.

Lee Wood: Ms. Wood addressed the financial impact of LD. She spent a great deal of effort, time, and money in search of a diagnosis for her illness, contracted in 1997 and finally diagnosed out of state. Without catastrophic illness insurance coverage, she was unable to get regular health insurance for 2 ½ years. She spent over \$7,000.00 each year for her treatment. She felt the Committee could have a great effect by addressing these issues with insurance companies. She pointed out that while at this point in her life she should be contributing to the tax base, she is actually a drain to the tax base. Thus, LD education for physicians and other health care professionals is critical to decrease the financial impact on the state and nation. Working people are not being adequately diagnosed and treated for LD and thus are not able to contribute to the economy.

Carol Martin: Ms. Martin was diagnosed with LD shortly after a tick-bite and 15 months later was diagnosed with *Bartonella*. She is concerned that the brochure does not list *Bartonella* as a coinfecting agent and thinks that DHS should be the first agency to mention *Bartonella* as a coinfecting agent. She and Diane Wilcox then performed a skit that they use when they give educational talks to school children, teaching them how to do tick checks.

Dan Deneen: Mr. Deneen recounted how it took two years to get his daughter diagnosed with LD. He wanted know why, with the billions dollars in the health care industry, we can't spend some of that money for radio and television notices. He applauds the Committee's efforts to educate physicians.

Sandy Frizzel: Ms. Frizzel has spent 30 years as a scientist working for the State of California, currently in forest management. She was diagnosed 1 ½ years ago with LD after spending eight months trying to get a diagnosis. She felt that proper information on LD had not been made available to her and this may have contributed to her getting the disease. She was also concerned that the number of reported cases of LD is much too low, and that the low numbers and decreasing trend presented in the *Action Report* is contrary to the increasing case number and trend in the U.S. This information may hinder physicians from getting the message that LD exists here in California. She was additionally concerned that State employees in resource agencies are not being offered the appropriate information on measures to take to avoid getting LD and are made to wear dark uniforms in the field, making tick detection difficult. She thanked the Committee for their efforts.

Patricia Deneen: Ms. Deneen recounted the difficulty her daughter faced in getting diagnosed with LD after weeks of vomiting and diarrhea. Her daughter finally obtained a diagnosis of LD out of state after it was recommended that they take their daughter to a psychiatrist in CA for her vomiting and diarrhea. Her daughter is facing great difficulty in finding a physician to help treat her here in California and has spent \$40,000 in the past 4 years to get treated. Ms. Deneen said it was heartbreaking to them to watch their daughter have to do all her own research, searching for help. She is hopeful the DHS will focus on education of medical students at major centers.

Terry Mitchell-Charonnat: Ms. Mitchell-Charonnat appreciated the map on the front of the brochure. She felt that the map should be piggy-backed in paycheck envelopes of all state employees and in health care professional license renewals. She suggested that the physician questionnaire should ask if a physician has seen a case of LD and also, DHS could have Lyme information offered at state recruiting efforts. She felt that healthcare is market-driven, and if the DHS educates the public, they will educate the physicians and motivate them to learn about Lyme disease.

Dr. Dana Caldwell: Dr. Caldwell had to leave but wanted it stated that it is important to educate pharmacists and use them as good source of information for patients.

Dr. Marylynn Barkley: Dr. Barkley is a reproductive endocrinologist from the University of California Davis. She presented a brief overview on some clinical studies on LD. Based on a Lyme patient case study, she summarized data suggesting that antibiotic therapy for LD results in an increased immune response as demonstrated by increased night sweats but, as the antibiotic therapy continues, the night sweats eventually decrease, taking approximately two years to eradicate. Increased night sweats were also associated with menses in women with Lyme or bacterial illness. Lack of a “gold standard” test for LD means that physicians must make decisions with uncertainty. Physicians must weigh the consequences of denying treatment to a sick patient who tests negative for LD, knowing that 20% will test false negative LD.

Myrna Vallejo: Ms. Vallejo expressed her disappointment with DHS and the Committee. She felt that essential information on the seriousness of LD and testing procedures was left out of the brochure.

The meeting was adjourned at 4:15 p.m.